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Gender Differences in Sarcoidosis: Symptoms, Quality of Life, and Medical Consumption

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ABSTRACT. The aim of this study was to examine gender differences in quality of life (QOL) and in constitutional symptoms that coincide with sarcoidosis. The study population included 1026 sarcoidosis patients—all members of the Dutch Sarcoidosis Society—who completed the WHOQOL-100 and a symptom checklist. Women experienced more symptoms than men. With regard to QOL, male and female patients who suffered from symptoms differed in the broader domains of Physical Health and Psychological Health. Specific facets reflected pain, sleep, positive affect, appearance, mobility, and activities of daily living. Future studies should focus on the different experience of the disease between male and female patients more extensively. Studies are needed to evaluate whether the differences in the present study between male and female sarcoidosis patients are caused by a subject selection bias or life style differences; have a genetic, hormonal or biological base; or just are an epiphenomenon. *[Article copies available for a fee from The Haworth Document Delivery Service: 1-800-342-9678. E-mail address: getinfo@haworthpressinc.com <Website: <http://www.haworthpressinc.com>>]*

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INTRODUCTION

The number of studies into health status and quality of life (QOL) has increased enormously over the last ten years. The focus of the majority of these investigations is on the influence of disease on QOL and health status. Generally, gender is often used only as a covariate (e.g., Matikka & Vesala, 1997; McCann, Russo, Benjamin, & Andrew, 1997) or as one of the characteristics for matching groups (e.g., Conroy, 1996). However, only few studies focussed on the possible role of gender. Haug and Folmar (1986) studied QOL in non-institutionalized elderly men and women. Results indicated that older women received less spousal support and had a substantially lower income. In addition, compared with males, women suffered more from health problems and demonstrated more cognitive and emotional losses. In a more recent study, Norum and Wist (1996) focussed on gender and treatment modalities in relation to the QOL of survivors of Hodgkin's disease. In contrast with expectations, female survivors reported better global QOL and lower fatigue scores than male survivors. Several reviews described gender differences in cause-specific mortality and morbidity (e.g., Verbrugge, 1985; Wingard & Cohn, 1990). For instance, gender differences were studied regarding aspects of QOL in cardiac patients (Kinney, Burfitt, Stullenbarger, Rees, & Debolt, 1996), elderly carers (Draper, Poulos, Poulos, & Ehrlich, 1996), genital herpes patients (Jadack, Keller, & Hyde, 1990), and patients with mental disorders (Linzer et al., 1996).

Chronic Non-Specific Lung Disease (CNSLD) has shown to have influenced health status substantially (Maillé, Kaptein, De Haes, & Everaerd, 1996). For example, Schrier, Dekker, Kaptein, and Dijkman (1990) found that elderly patients with CNSLD experienced substantial problems in the area of physical as well as psychological functioning and reported more dysfunction compared to a healthy control group. In accordance with other studies (e.g., Guyatt, Townsend, Berman, & Pugsley, 1987; Ketelaars et al., 1996; McSweeney, Grant, Heaton, Adams, & Timms, 1982; Williams & Bury, 1989), Okubadejo, Jones, and Wedzicha (1996) recently reported impairment in most areas of health status in patients with chronic obstructive pulmonary disease (COPD). However, gender differences have been given very little attention. An exception is the study by Isoaho, Keistinen, Laippala, and Kivela (1995) who found that in female COPD patients, in contrast to males, the disease was related to disability, feelings of dissatisfaction with life, and low satisfaction with their marital relationship. In the investigation by Williams and Bury (1989), male COPD patients reported more problems in the

area of work, while female COPD patients had more problems in the area of domestic responsibilities. Finally, research by Leidy and Traver (1995) indicated that somatic symptoms predicted health status in female COPD patients only.

Sarcoidosis is a disorder of unknown origin most frequently occurring in the lung. Clinical manifestations of sarcoidosis depend on the intensity of the inflammation and organ systems affected. Sarcoidosis presents itself in a variety of ways. It is estimated that about 20% to 50% of the patients have respiratory symptoms including cough, dyspnea, chest pain, wheezing, and chest discomfort (Thomas & Hunninghake, 1987). Furthermore, fatigue, arthralgia, and erythema nodosum are common features of sarcoidosis which show, however, some variation across countries (e.g., Fité et al., 1996; Pietinalho, Ohmichi, Hiraga, Löfroos, & Selroos, 1996; Wirnsberger, De Vries, Wouters, & Drent, 1998). The disease is probably more common amongst women, although this also appears to vary from country to country (e.g., Du Bois, 1995; Hillerdal, Nöu, Osterman, & Schmekel, 1984). The peak incidence of sarcoidosis occurs between the ages 20 and 40 in both men and women, with a second lower and broader peak in women between 45 and 65 years of age (Hillerdal et al., 1984; Klonoff & Kleinhenz, 1993). In The Netherlands, the prevalence of sarcoidosis is estimated to be 20-30/100,000, i.e., between 3,200 and 4,800 patients (James, 1992). Only recently several investigations into the QOL and health status of sarcoidosis patients were conducted. Drent et al. (1998) demonstrated that sarcoidosis patients were limited in their physical and psychological functioning. They appeared to be affected predominantly in the areas of sleep and rest, recreation and pastime, employment, alertness behaviour, emotional behaviour and social interaction compared to a control group. With regard to gender differences, female patients showed more emotional problems as well as body care and movement problems than males. Wirnsberger, De Vries, Breteler et al. (1998) found that fatigue was a substantial problem in sarcoidosis. Moreover, compared to the healthy controls, patients with constitutional complaints had more problems with their mobility, activities of daily living, working capacity and recreation than sarcoidosis patients without any current symptoms. Furthermore, female sarcoidosis patients reported more sleep problems than male patients.

As sarcoidosis often resolves spontaneously, therapeutic intervention is not necessary in all patients (Müller-Quernheim, 1996). There is general agreement that patients with extra pulmonary manifestations, such as involvement of eyes or heart, should undergo treatment (Du Bois, 1995). Moreover, therapy is indicated with persistent hypercalcaemia (Costabel & Teschler, 1997; Sharma, 1996) or rapid deterioration of pulmonary function tests (Hunninghake et al., 1994; Newman, Rose, & Maier, 1997). Corticosteroids

are considered the most effective therapy (Yamamoto, Sharma, & Hosada, 1991). However, corticosteroids have significant side effects (Costabel & Teschler, 1997) and their effect on long-term outcome of sarcoidosis are controversial (Eule, Weinecke, & Roth, 1986; Gibson et al., 1996; Gottlieb, Israel, Steiner, Triolo, & Patrick, 1997). Occasionally, non-steroidal anti-inflammatory drugs (NSAIDs) are prescribed to treat minimal disease (Baughman & Lower, 1997). This may relieve arthralgia and muscle pain and have an anti-inflammatory effect in sarcoidosis.

Differences in reported symptoms between male and female patients have been studied by, for instance, O'Keefe, Taley, Zinsmeister, and Jacobsen (1995) who demonstrated that gender differentiated between asymptomatic and symptomatic groups with bowel disorders. The results of pulmonary studies are inconsistent. Whilst Sherrill, Lebowitz, Knudson, and Burrows (1993) and Janson-Bjerklie, Carrieri, and Hudes (1986) reported gender differences in disease symptoms, Van den Boom et al. (1998) found no such differences between COPD patients who did or did not consult their general practitioners concerning respiratory symptoms. Moreover, gender differences were also found in married people (Mookherjee, 1997), homeless people (Ritchey, La Gory, & Mullis, 1991) and with regard to sensitive cough reflex, in healthy subjects (Dicpinigaitis & Rauf, 1998).

In sarcoidosis, less is known about gender differences in QOL and constitutional symptoms. Additionally, a thorough knowledge of gender differences in medication prescription is lacking. The aim of this study, therefore, was to evaluate gender differences with regard to the constitutional symptoms, QOL, and medical consumption of sarcoidosis patients.

METHODS

Subjects

All 1,755 members of the Dutch Sarcoidosis Society (DSS) suffering from sarcoidosis were sent a test-booklet together with a letter from the DSS in which they were asked to participate in an in-depth study on quality of life and symptoms. Of the 1,093 patients (62.3%) who responded, 1,026 (58.5% of the total group) completed the questionnaires. The remaining 67 people gave a number of reasons why they did not wish to participate in the study. The main reasons included (i) the innumerable list of questions (14), (ii) a lack of time (10), (iii) the absence of symptoms (9), and (iv) the fact that the diagnosis was made quite some time ago. Eight people returned the test-booklet without giving any reason. Because the DSS does not register the sex of its members, unfortunately no information on this point is available about the non-response group.

Measures

All participants completed the World Health Organization Quality of Life assessment instrument-100 (WHOQOL-100; Dutch version De Vries & Van Heck, 1995), a cross-culturally developed generic multidimensional QOL measure (WHOQOL group, 1994). This consists of 100 items assessing 24 facets of QOL within six domains (Physical Health, Psychological Health, Level of Independence, Social Relationships, Environment, and Spirituality/Religion/Personal Beliefs) and a general evaluative facet (Overall Quality of Life and General Health) (WHOQOL group, 1995). Each facet is represented by four items. The response scale is a 5-point Likert scale. Scores on each facet and domain may range from 4 to 20. The reliability and validity of the instrument are high (De Vries & Van Heck, 1997).

In addition, the participants were asked to complete a symptom checklist. They needed to indicate whether they experienced any of 12 physical symptoms such as fatigue, arthralgia, cough, muscle pain and weakness, and chest pain. Finally, subjects were requested to answer questions concerning use of medication.

Statistical Procedure

Data are expressed as mean \pm SD. In order to detect statistically significant differences data were analysed using Student *t*-tests, Chi-square tests, loglinear analyses, and ANCOVA, unless stated otherwise. Covariates were age, marital status, use of corticosteroids, and symptoms. A *p*-value < .01 was considered to be statistically significant, unless stated otherwise. All analyses were performed using the Statistical Package for Social Sciences (SPSS).

RESULTS

Demographic and medical data are summarized in Table 1. The results indicated that more women than men reported symptoms ($\chi^2 (1, N = 961) = 5.6, p < .05$) and that women were on average older ($t (848.67) = 3.1, p < .005$). With regard to marital status, it appeared that more men than women were living together with a partner ($\chi^2 (1, N = 971) = 8.5, p < .005$). In addition, when age and marital status were entered as covariates, women also appeared to report more symptoms than men ($F (1, 947) = 20.5, p < .001$). The duration of the illness (chronicity) was not related to gender, experiencing symptoms, or the number of symptoms.

Looking at the type of current symptoms reported, it appeared that women complained of starting problems, fatigue, skin problems, chest, abdominal,

TABLE 1. Summary of Reported Symptoms, Listed Medications, and Demographic Characteristics of the Sarcoidosis Population Studied. Male (n = 358) and Female (n = 617) Respondents Are Presented Separately

	Females (%)	Males (%)	χ^2	$p <$
Symptoms				
Muscle pain	271 (44.7)	124 (34.8)	3.2	ns
Chest pain	202 (33.3)	74 (20.8)	12.1	0.001
Abdominal pain	91 (15.0)	28 (7.9)	11.4	0.001
Arthralgia	367 (60.5)	162 (45.5)	19.8	0.001
Muscle weakness	150 (24.7)	76 (21.3)	0.5	ns
Starting problems	235 (38.7)	97 (27.2)	14.8	0.001
Fatigue	469 (77.3)	251 (70.5)	7.3	0.01
Reduced exercise capacity	331 (54.5)	181 (50.8)	1.1	ns
Erythema nodosum	122 (20.1)	49 (13.8)	6.7	0.01
Heart complaints	67 (11.0)	32 (9.0)	0.1	ns
Eye problems	187 (30.8)	88 (24.7)	2.3	ns
Dry mouth	117 (19.3)	42 (11.8)	3.1	ns
Dyspnea	463 (75.0)	247 (69.0)	3.1	ns
Cough	200 (32.4)	100 (27.9)	1.1	ns
Medication				
Eye drops	171 (29.4)	64 (18.8)		
Oral steroids	337 (57.7)	222 (65.5)		
Heart medication	55 (9.4)	34 (10.1)		
Pain killers	240 (41.1)	88 (26.0)		
Psychological/ neurological medication	82 (14.0)	37 (10.5)		

TABLE 1 (continued)

	Females (%)	Males (%)	
Non-steroidal anti-inflammatory drugs	236 (40.4)	86 (25.4)	
Bronchodilators	185 (31.7)	106 (31.3)	
	Demographic information		Total group
Age range	16-74	21-71	16-74
mean \pm SD	47.7 \pm 12.3	45.4 \pm 10.2	46.7 \pm 11.6
Years since diagnosis	11.7 \pm 10.6	13.0 \pm 11.4	12.2 \pm 10.9
Smoking/non-smoking/missing	30/550/37	17/313/28	47/863/65
Living with partner/alone/missing	490/123/4	312/46/0	805/174/4
<i>Note.</i> Loglinear analyses with gender for each symptom (age and marital status as covariates). ns = not significant.			

and joint pain more often than men (see Table 1). Subsequently, the patient group was divided into two groups: a group with current symptoms and a group without current symptoms. In the patient group experiencing current symptoms, more females than males reported using eye drops ($\chi^2 (1, N = 829) = 12.4, p < .001$), pain killers ($\chi^2 (1, N = 831) = 21.5, p < .0001$), and non-steroidal anti-inflammatory drugs (NSAIDs) ($\chi^2 (1, N = 831) = 21.4, p < .0001$) whilst males more often used oral steroids ($\chi^2 (1, N = 831) = 5.5, p < .05$). In addition, female patients more often received treatment other than medication, e.g., physiotherapy ($\chi^2 (1, N = 797) = 10.0, p < .005$). In the patient group experiencing no current symptoms, females reported a more frequent use of psychological/neurological medication ($\chi^2 (1, N = 79) = 5.2, p < .05$).

Within the group of patients not using corticosteroids, female sarcoidosis patients reported more arthralgia ($\chi^2 (1, N = 363) = 5.6, p < .05$) and erythema nodosum ($\chi^2 (1, N = 363) = 17.1, p < .0001$). In the patient group using corticosteroids, a large number of symptoms were reported more by female than male patients (see Table 2). Furthermore, male patients who used corticosteroids reported more reduced exercise capacity and *less* arthralgia, muscle weakness, starting problems, muscle pain, and heart problems than those males who did not use oral steroids (see Table 2). Within the group of female patients, using corticosteroids was related to increased eye problems ($\chi^2 (1, N = 578) = 5.2, p < .05$), reduced exercise capacity ($\chi^2 (1, N = 578) = 6.1, p < .01$), and cough ($\chi^2 (1, N = 573) = 8.4, p < .005$).

Analyses concerning QOL scores revealed that men scored higher than women in the domains of Physical Health and Psychological Health and men were more satisfied with their quality of sleep and their physical appearance. Moreover, they indicated a higher sense of mobility and capacity to perform daily activities. Women reported experiencing more pain but had more positive feelings (see Table 3). No significant differences emerged in the domains Social Relationships, Environment, and Spirituality/Religion/Personal Beliefs.

The QOL of respondents using corticosteroids was lower on the global QOL and health facet ($t (830.73) = 3.26, p < .005$), the domain Level of Independence ($t (907) = 4.98, p < .001$), and the facets Energy and Fatigue ($t (907) = 2.95, p < .005$), Dependence on Medication or Treatments ($t (906) = 7.53, p < .001$), and Working Capacity ($t (903) = 3.88, p < .001$). Within the group of male sarcoidosis patients, differences were found only for the domain Level of Independence ($t (327) = 2.70, p < .01$) and its facets Dependence on Medication or Treatments ($t (328) = 4.08, p < .001$) and Working Capacity ($t (260.60) = 2.70, p < .01$). In all instances, those male patients who used corticosteroids had lower QOL scores. Between female sarcoidosis patients who did and did not use corticosteroids more QOL differences emerged. At domain level, female patients using corticosteroids had lower scores on Physical Health ($t (573) = 3.66, p < .001$) and Level of Independence ($t (571) = 4.73, p < .001$). At facet level, six differences between female sarcoids who did or did not use corticosteroids were observed. Females who used oral steroids had lower QOL scores on the global QOL and health facet ($t (572) = 3.26, p < .005$), Energy and Fatigue ($t (571) = 3.48, p < .005$), Bodily Image and Appearance ($t (554.13) = 3.22, p < .005$), Mobility ($t (574) = 3.10, p < .005$), Dependence on Medication or Treatments ($t (569) = 6.47, p < .001$), and Working Capacity ($t (568) = 3.45, p < .005$).

Since it is known from a previous study (Wirnsberger, De Vries, Breteler et al., 1998) that current symptoms are negatively related to QOL, the differences between female and male patients within the sarcoidosis groups and with or without current symptoms were examined separately. The results

TABLE 2. Differences in Symptom Reporting Between Females and Males Using Corticosteroids and Between Males Using or Not Using Corticosteroids (Chi-square tests)

Symptoms	Using corticosteroids		χ^2	$p <$
	Females (%)	Males (%)		
Muscle pain	139 (41.9)	65 (29.4)	8.8	0.005
Abdominal pain	44 (13.3)	14 (6.3)	6.8	0.01
Arthralgia	195 (58.7)	85 (38.5)	21.8	0.00001
Starting problems	125 (37.7)	52 (23.5)	12.2	0.001
Fatigue	288 (86.7)	170 (76.9)	9.0	0.005
Erythema nodosum	131 (39.5)	44 (19.9)	23.4	0.00001
Heart complaints	43 (13.0)	14 (6.3)	6.3	0.05
Eye problems	139 (41.9)	65 (29.4)	8.8	0.005
Dyspnea	280 (85.6)	163 (75.8)	8.4	0.005
Cough	211 (63.9)	110 (50.5)	9.8	0.005
Males				
	No corticosteroids	Corticosteroids		
Muscle pain	48 (41.0)	65 (29.4)	4.6	0.05
Arthralgia	64 (55.2)	91 (41.2)	7.4	0.01
Muscle weakness	32 (27.6)	41 (18.6)	6.4	0.01
Starting problems	43 (36.8)	52 (23.5)	6.6	0.01
Reduced exercise capacity	47 (40.2)	117 (52.9)	5.0	0.05
Heart complaints	16 (13.7)	14 (6.3)	5.1	0.05

showed that no differences between male and female sarcoidosis patients emerged in the group without any current symptoms. In contrast, the gender differences reported for the total sarcoidosis group also emerged for the sarcoidosis group with current symptoms, with the exception of the domain score Psychological Health (see Table 3).

TABLE 3. Differences in QOL Between Male (n = 300) and Female (n = 541) Sarcoidosis Patients with Current Symptoms

	Female patients ^a	Male patients ^a	<i>F</i>	<i>p</i> <
<i>Physical Health</i>	11.7 (2.4)	12.4 (2.5)	13.4	0.001
Pain and Discomfort	12.2 (2.7)	11.5 (2.9)	10.1	0.005
Sleep and Rest	13.8 (3.9)	14.7 (3.8)	9.0	0.005
<i>Psychological Health</i>	13.8 (2.2)	14.2 (2.1)	7.5	0.01
Positive Feelings	13.9 (2.4)	13.4 (2.3)	6.9	0.01
Bodily Image and Appearance	14.9 (3.7)	16.5 (3.1)	41.4	0.001
<i>Level of Independence</i>				
Mobility	13.7 (3.5)	14.5 (3.5)	7.9	0.01
Activities of Daily Living	12.2 (3.3)	13.0 (3.3)	10.0	0.005

Note: Domains are printed in italics. Analyses of covariance (covariates: age, marital status, symptoms, and use of corticosteroids).

^aValues represent mean scores.

DISCUSSION

The aim of this study was to examine gender differences regarding symptoms and QOL of sarcoidosis patients. Gender appeared to be related to the presence of symptoms, the number of symptoms, and in some cases to the type of symptoms reported by sarcoidosis patients. Concerning the *type* of symptoms, women reported more erythema nodosum, starting problems, fatigue, arthralgia, chest and abdominal pain. These results are consistent with trends in the general population that women report more symptoms (Ritchey et al., 1991) and are more emotionally expressive (Edwards, Nazroo & Brown, 1998). It is tempting to speculate that men and women cope differently with symptoms. This view is supported by a study amongst women who received coronary artery bypass surgery. They appeared to attend to different symptoms and signs as cues to resuming activity during recovery and rehabilitation than

men (Hawthorne, 1993). Future research should focus on gender differences in seeking medical aid and the attendance to symptoms in more depth.

Female sarcoidosis patients *with* current symptoms more often reported the use of eye drops, pain killers, and NSAIDs. The prescription of NSAIDs is consistent with the symptoms reported by female sarcoidosis patients. Moreover, female patients *experiencing no* current symptoms reported a more frequent use of psychological or neurological medication compared to male patients. This phenomenon could not be explained by differences in reported neurological or psychological problems. Male sarcoidosis patients more frequently used oral steroids. This could not be explained by a difference in presenting symptoms between male and female patients. Furthermore, Wirnsberger, De Vries, Wouters et al. (1998) also did not find a relationship between reported symptoms and the use of corticosteroids. It is possible that male patients are prescribed corticosteroids in order to accelerate their return to work. In contrast with the present results, Drent and colleagues (1998) reported no gender differences regarding the use of corticosteroids.

The QOL of sarcoidosis patients using corticosteroids was lower than patients who did not use oral steroids in a number of areas. In the literature (e.g., Mitchell & O'Keane, 1998), a positive relationship was found between the use of corticosteroids and depression. It is possible that a more negative outlook on QOL in a number of areas is a reason for pulmonary physicians to prescribe oral steroids. However, this does not explain the fact that more QOL differences could be demonstrated in female patients compared with male patients, irrespective of the use of corticosteroids.

In the present study, gender played a role in a number of QOL domains and facets. Differences emerged in the physical and psychological domains. More specifically, differences were found for pain, sleep, positive feelings, bodily image, mobility, and daily life activities. In all these areas, QOL was more impaired in females compared to males. The number of QOL differences was much greater in the present study than in the population of 64 sarcoidosis patients studied by Wirnsberger, De Vries, Breteler et al. (1998). Using the WHOQOL-100, the same gender difference was found solely with regard to sleep. However, the sample size of their study population was much smaller, and more importantly, the majority of the sarcoidosis patients were male.

More female than male sarcoidosis patients reported symptoms. Moreover, female patients with symptoms had a lower QOL in a number of areas. The importance of current symptoms for patients' QOL and health status has already been established in previous studies (De Vries, Drent, Van Heck, & Wouters, 1998; Leidy & Traver, 1995; Wirnsberger, De Vries, Breteler et al., 1998). However, from the present study it became clear that a patient's gender is crucial in determining QOL.

A difference in physical and psychological burden might explain the gender differences in symptoms and QOL. However, female patients did not experience more life events than males (data not shown). In addition, female and male sarcoidosis patients did not differ in illness duration or absence from work through illness (data not shown). It may well be that female patients experience more difficulties when combining domestic activities with working outside the home. Furthermore, domestic chores may be more physically demanding than, for instance, administrative work. Further research into these possible causes of the gender differences is needed.

The present study has a number of limitations which are mainly related to subject selection. The patients in the present study appeared to suffer from chronic sarcoidosis and a high percentage of them indicated having one or more physical symptoms. This might suggest that sarcoidosis patients decide to become members of the patient organisation when the disease is chronic and they are experiencing symptoms. Confronted with the disease patients may need more information about its many different aspects than persons with transitory sarcoidosis. Another factor may be that patients who live alone seek contact with other patients through the organisation. Furthermore, the members who did not participate in the present study (42%), might not experience symptoms. Unfortunately, this idea cannot be checked within the present study since there is no information available regarding the occurrence of symptoms in the non-response group. In the present study, twice as many female than male patients participated. There are probably also more female than male patients in the overall sarcoidosis population (e.g., DuBois, 1995), but exactly how many more is unknown, because there is no chest radiograph screening program in The Netherlands. In addition, based on the existing literature, it is difficult to identify which factors determine male and female participation in research. A possible factor may be that sick females are more inclined than sick males to participate in studies. However, this remains speculative. Concerning these limitations, the outcome of the present study must not be overgeneralised. However, in a previous study (De Vries et al., 1998) a group of sarcoidosis hospital outpatients were compared with a group of DSS members. Results showed that when groups were matched for age, gender, and current symptoms, differences in the vast majority of QOL facets were absent. The gender differences observed in the members of the DSS who participated in the present study cannot be ignored as the vast majority of the respondents reported visiting a pulmonary physician on a regular basis which may demand more time and effort on the physician's part (data not shown).

It is possible that sarcoidosis may behave differently in female and male patients. If this is true, this may account for the gender differences with

regard to symptoms. However, as far as the authors know this has not yet been studied.

In conclusion, male and female sarcoidosis patient members of the DSS experienced different current symptoms and QOL. Female patients reported the presence of more symptoms more often and the nature of these symptoms also differed from those of male patients. In addition, female patients had a lower QOL in the areas of physical and psychological health, particularly with regard to pain, sleep, positive feelings, self-esteem, bodily image, mobility, and daily life activities. When the group was divided according to whether or not symptoms were present, no gender differences emerged within that patient group where symptoms were absent. Medication also differed between female and male patients. In patients with current symptoms females were prescribed more eye drops, pain killers, and NSAIDs, whilst males received more frequently corticosteroids. Future studies should focus on the different experience of the disease between male and female patients more extensively. Studies are needed to evaluate whether the differences in the present study between male and female sarcoidosis patients are caused by a subject selection bias or life style differences; have a genetic, hormonal or biological base; or just are an epiphenomenon. Studying gender differences should facilitate discovery of ways to avoid and treat current and future health problems (cf. Baum & Grunberg, 1991).

REFERENCES

- Baughman, R.P. & Lower, E.E. (1997). Alternatives to corticosteroids in the treatment of sarcoidosis. *Sarcoidosis*, 14, 121-130.
- Baum, A. & Grunberg, N.E. (1991). Gender, stress, and health. *Health Psychology*, 10, 80-85.
- Conroy, J.W. (1996). The small ICF-MR program: Dimensions of quality and cost. *Mental Retardation*, 34, 13-26.
- Costabel, U. & Teschler, H. (1997). Biochemical changes in sarcoidosis. *Clinics in Chest Medicine*, 18, 827-842.
- De Vries, J., Drent, M., Van Heck, G.L., & Wouters, E.F.M. (1998). Quality of life in sarcoidosis: A comparison between members of a patient organisation and a random sample. *Sarcoidosis Vasculitis and Diffuse Lung Diseases* (in press).
- De Vries, J. & Van Heck, G.L. (1995). *Nederlandse WHOQOL-100 [Dutch WHOQOL-100]*. Tilburg: Tilburg University.
- De Vries, J. & Van Heck, G.L. (1997). The World Health Organization Quality of Life assessment instrument (WHOQOL-100): Validation study with the Dutch version. *European Journal of Psychological Assessment*, 13, 164-178.
- Dicpinigaitis, P.V. & Rauf, K. (1998). The influence of gender on cough reflex sensitivity. *Chest*, 113, 1319-1321.
- Draper, B.M., Poulos, R.G., Poulos, C.J., & Ehrlich, F. (1996). Risk factors for stress in elderly caregivers. *International Journal of Geriatric Psychiatry*, 11, 227-231.

- Drent, M., Wirnsberger, R.M., Breteler, M.H.M., Kock, L.M.M., De Vries, J., & Wouters, E.F.M. (1998). Quality of life and depressive symptoms in patients suffering from sarcoidosis. *Sarcoidosis Vasculitis and Diffuse Lung Diseases*, 15, 59-66.
- Du Bois, R.M. (1995). Sarcoidosis. In E.H. Walters & R.M. du Bois (Eds.), *Immunology and management of interstitial lung diseases* (pp. 97-122). London: Chapman & Hall.
- Edwards, A.C., Nazroo, J.Y., & Brown, G.W. (1998). Gender differences in marital support following a shared life event. *Social Science & Medicine*, 46, 1077-1085.
- Eule, H., Weinecke, A., & Roth, I. (1986). The possible influence of corticosteroid therapy on the natural course of pulmonary sarcoidosis. *Annals of the New York Academy of Sciences*, 465, 695-701.
- Fité, E., Alsina, J.M., Maña, J., Pujol, R., Ruiz, J., & Morera, J. (1996). Epidemiology of sarcoidosis in Catalonia: 1979-1989. *Sarcoidosis Vasculitis and Diffuse Lung Diseases*, 13, 153-158.
- Gibson, G.J., Prescott, R.J., Muers, M.F., Middleton, W.G., Mitchell, D.N., Connelly, C.K., & Harrison, B.D.W. (1996). British Thoracic Society Sarcoidosis study: Effects of long term corticosteroid treatment. *Thorax*, 51, 238-247.
- Gottlieb, J.E., Israel, H.L., Steiner, R.M., Triolo, J., & Patrick, H. (1997). Outcome in sarcoidosis: The relationship of relapse to corticosteroid therapy. *Chest*, 111, 623-631.
- Guyatt, G.H., Townsend, M., Berman, L.B., & Pugsley, S.O. (1987). Quality of life in patients with chronic airflow limitation. *British Journal of Diseases of the Chest*, 81, 45-54.
- Haug, M.R. & Folmar, S.J. (1986). Longevity, gender, and life quality. *Journal of Health and Social Behavior*, 27, 332-345.
- Hawthorne, M.H. (1993). Women recovering from coronary artery bypass surgery. *Scholarly Inquiry for Nursing Practice*, 7, 223-244.
- Hillerdal, G., Nöu, E., Osterman, K., & Schmekel, B. (1984). Sarcoidosis: Epidemiology and prognosis. A 15-year European study. *American Review of Respiratory Diseases*, 130, 29-32.
- Hunninghake, G.W., Gilbert, S., Pueringer, R., Dayton, C., Floerchinger, C., Helmers, R., Merchant, R., Wilson, J., Galvin, J., & Schwartz, D. (1994). Outcome of the treatment for sarcoidosis. *American Journal Respiratory Critical Care Medicine*, 149, 893-898.
- Isoaho, R., Keistinen, T., Laippala, P., & Kivela, S.L. (1995). Chronic obstructive pulmonary disease and symptoms related to depression in elderly persons. *Psychological Reports*, 76, 287-297.
- Jadack, R.A., Keller, M.L., & Hyde, J.S. (1990). Genital herpes: Gender comparisons and the disease experience. *Psychology of Women Quarterly*, 14, 419-434.
- James, D.G. (1992). Epidemiology of sarcoidosis. *Sarcoidosis*, 9, 79-87.
- Janson-Bjerklie, S., Carrieri, V.K., & Hudes, M. (1986). The sensations of pulmonary dyspnea. *Nursing Research*, 35, 154-159.
- Ketelaars, C.A.J., Schlösser, M.A.G., Mostert, R., Huyer Abu-Saaid, H., Halfens, R.J.G., & Wouters, E.F.M. (1996). Determinants of health-related quality of life in patients with chronic obstructive pulmonary disease. *Thorax*, 51, 39-43.
- Kinney, M., Burfitt, S.N., Stullenbarger, E., Rees, B., & Debolt, M.R. (1996). Quality of life in cardiac patient research: A meta-analysis. *Nursing Research*, 45, 173-180.
- Klonoff, E.A. & Kleinhenz, M.E. (1993). Psychological factors in sarcoidosis: The relationship between life stress and pulmonary function. *Sarcoidosis*, 10, 118-124.

- Leidy, N.K. & Traver, G.A. (1995) Psychophysiologic factors contributing to functional performance in people with COPD: Are there gender differences? *Research in Nursing and Health*, 18, 535-546.
- Linzer, M., Spitzer, R., Kroenke, K., Williams, J.B., Hahn, S., Brody, D., & Degruy, F. (1996). Gender, quality of life, and mental disorders in primary care: Results from the Prime-MD-1000 Study. *American Journal of Medicine*, 101, 526-533.
- Maillé, A.R., Kaptein, A.A., De Haes, J.C.J.M., & Everaerd, W.Th.A.M. (1996). Assessing quality of life in chronic non-specific lung disease: A review of empirical studies published between 1980 and 1994. *Quality of Life Research*, 5, 287-301.
- Matikka, L.M. & Vesala, H.T. (1997). Acquiescence in quality-of-life interviews with adults who have mental retardation. *Mental Retardation*, 35, 75-82.
- McCann, B.S., Russo, J., Benjamin, G., & Andrew, H. (1997). Hostility, social support, and perceptions of work. *Journal of Occupational Health Psychology*, 2, 175-185.
- McSweeney, A.J., Grant, I., Heaton, R.K., Adams, K.M., & Timms, T.M. (1982). Life quality of patients with chronic obstructive pulmonary disease. *Archives of Internal Medicine*, 142, 473-478.
- Mitchell, A. & O'Keane, V. (1998) Steroids and depression: Glucocorticoid steroids affect behaviour and mood. *British Medical Journal*, 316, 244-245.
- Mookherjee, H.N. (1997). Marital status, gender, and perception of well-being. *Journal of Social Psychology*, 137, 95-105.
- Müller-Quernheim, J. (1996). The cytokine network in sarcoidosis. *European Cytokine Network*, 7, 13-26.
- Newman, L.S., Rose, C.S., & Maier, L.A. (1997). Sarcoidosis. *New England Journal of Medicine*, 336, 1224-1234.
- Norum, J. & Wist, E.A. (1996). Quality of life in survivors of Hodgkin's disease. *Quality of Life Research*, 5, 367-374.
- O'Keefe, E.A., Taley, N.J., Zinsmeister, A.R., & Jacobsen, S.J. (1995). Bowel disorders impair functional status and quality of life in the elderly: A population-based study. *Journals of Gerontology: Series A: Biological Sciences and Medical Sciences*, 50A, M184-M189.
- Okubadejo, A.A., Jones, P.W., & Wedzicha, J.A. (1996). Quality of life in patients with chronic obstructive pulmonary disease and severe hypoxaemia. *Thorax*, 51, 44-47.
- Pietinalho, A., Ohmichi, M., Hiraga, Y., Löfroos, A-B., & Selroos, O. (1996). The mode of presentation of sarcoidosis in Finland and Hokkaido, Japan: A comparative analysis of 571 Finnish and 686 Japanese patients. *Sarcoidosis Vasculitis and Diffuse Lung Diseases*, 13, 159-166.
- Ritchey, F.J., La Gory, M., & Mullis, J. (1991). Gender differences in health risks and physical symptoms among the homeless. *Journal of Health and Social Behavior*, 32, 33-48.
- Schrier, A.C., Dekker, F.W., Kaptein, A.A., & Dijkman, J.H. (1990). Quality of life in elderly patients with chronic non specific lung disease seen in family practice. *Chest*, 98, 894-899.
- Sharma, O.P. (1996). Vitamin D, calcium, and sarcoidosis. *Chest*, 109, 535-539.
- Sherrill, D.L., Lebowitz, M.D., Knudson, R.J., & Burrows, B. (1993). Longitudinal methods for describing the relationship between pulmonary function, respiratory

- symptoms and smoking in elderly subjects: The Tucson study. *European Respiratory Journal*, 6, 342-348.
- Thomas, P.D. & Hunninghake, G.W. (1987). Current concepts of the pathogenesis of sarcoidosis. *American Review Respiratory Disease*, 135, 747-760.
- Van den Boom, G., Rutten-Van Mölken, M.P.M.H., Tirimanna, P.R.S., Van Schayck, C.P., Folgering, H., & Van Weel, C. (1998). Association between health-related quality of life and consultation for respiratory symptoms: Results from the DIM-CA programme. *European Respiratory Journal*, 11, 67-72.
- Verbrugge, L.M. (1985). Gender in health: An update on hypotheses and evidence. *Journal of Health and Social Behavior*, 26, 156-182.
- WHOQOL group (1994). Development of the WHOQOL: Rationale and current status. *International Journal of Mental Health* [Special issue: Quality of Life Assessment: Cross-cultural Issues-2], 23, 24-56.
- WHOQOL group (1995). The World Health Organization Quality of Life assessment (WHOQOL): Position paper from the World Health Organization. *Social Science and Medicine* [Special Issue on Health-related quality of life What is it? and How should we measure it?], 41, 1403-1409.
- Williams, S.J. & Bury, M.R. (1989). Impairment, disability and handicap in chronic respiratory illness. *Social Science and Medicine*, 29, 609-616.
- Wingard, D.L. & Cohn, B.A. (1990). Variations in disease-specific sex morbidity and mortality ratios in the United States. In M.G. Ory and H.R. Warner (Eds.), *Gender, health, and longevity: Multidisciplinary perspectives* (pp. 25-37). New York: Springer.
- Wirnsberger, R.M., De Vries, J., Wouters, E.F.M., & Drent, M. (1998). Clinical presentation of sarcoidosis in the Netherlands: An epidemiological study. *The Netherlands Journal of Medicine*, 53, 53-60.
- Wirnsberger, R.M., De Vries, J., Breteler, M.H.M., Van Heck, G.L., Wouters, E.F.M., & Drent, M. (1998). Evaluation of quality of life of sarcoidosis patients. *Respiratory Medicine*, 92, 750-756.
- Yamamoto, M., Sharma, O., & Hosada, Y. (1993). The 1991 descriptive definition of sarcoidosis. *Sarcoidosis*, 9, 33-34.